

# Online Research @ Cardiff

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <https://orca.cardiff.ac.uk/id/eprint/99489/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Shanmugaratnam, Shiva H. and Edwards, Adrian G. ORCID:  
<https://orcid.org/0000-0002-6228-4446> 2016. Ethical aspects of risk  
communication. *Medicine* 44 (10) , pp. 607-610.  
10.1016/j.mpmed.2016.07.005 file

Publishers page: <http://dx.doi.org/10.1016/j.mpmed.2016.07.005>  
<<http://dx.doi.org/10.1016/j.mpmed.2016.07.005>>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies.

See

<http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



## Ethical aspects of risk communication

Shiva H Shanmugaratnam

Adrian Edwards

**Shiva H Shanmugaratnam nMRCGP** is a General Practitioner and Associate Academic Fellow at Cardiff University, UK. Competing interests: none declared.

**Adrian Edwards PhD MRCGP** is a Professor of General Practice at the Division of Population Medicine, Cardiff University, UK. Competing interests: none declared.

### Abstract

Clinical decision-making is becoming increasingly complex because of greater patient access to information, more clinical options and the emphasis on patient-centred care with informed decision-making. Risk communication should form part of evidence-based clinical practice, and it is important to think about what happens when clinicians adopt different consultation approaches. In this article, the ethical consequences of risk communication are analysed by looking at how the paternalistic and shared decision-making models of consultation demonstrate different ethical implications, based around a clinical scenario. To do this, we have applied the ethical principles of autonomy, utility and justice to these models. We show that the different models of consultation place varying degrees of emphasis on risk communication, patient autonomy and biomedical utility. This has implications for the way care is delivered both for the individual patient and for the population as a whole.

### Keywords

Biomedical ethics; paternalism; patient-centred care; personal autonomy; risk assessment; utilitarianism

### Introduction

Risk is defined as the probability that a hazard will give rise to harm. Risk communication is a two-way discussion about risk that enables a better understanding of the risk in question. The goals of risk communication are to share information, change beliefs and behaviour where relevant and enable patients to make informed decisions based on understanding the risks.

Risk communication is commonly used in clinical practice. There is a substantial evidence base describing the competencies required to perform it effectively.<sup>1</sup> Examples of risk communication include a discussion of cardiovascular risk before commencing a statin for primary prevention of cardiovascular disease, or a discussion of breast cancer risk in an asymptomatic patient who is considering screening.

The National Institute for Health and Care Excellence (NICE) emphasizes that clinicians should take into account patients' needs, values, opinions and preferences, and that patients should be enabled to make informed decisions regarding their care. There is promising evidence to show that effective risk communication facilitates individualized goal-setting, shared decision-making and improved adherence to treatment. Different clinicians employ different consultation styles with their patients. These different styles incorporate risk communication in different ways and place differing levels of importance on it.

Communication of risk involves ethical choice. If patients are given all the relevant information and encouraged to make decisions based on this, will this always be helpful or could this be detrimental to someone's health in comparison with the clinician making the decision alone? Might the responsibility of the decision-making worry the patient? What implications does informed decision-making have on healthcare costs and public health?

Here, we discuss the varying degrees to which risk communication is used in different consultation approaches and analyse their ethical implications.

### **An illustrative case**

As stated, risk messages are common in clinical practice. Table 1 outlines a clinical scenario in which risk communication might be employed.

### **Different consultation approaches and risk communication**

Doctors use a variety of consultation approaches, and these can vary in risk communication. In the *paternalistic model*, the doctor listens to the patient's story, makes a decision about the nature of the problem and then uses their knowledge to provide the care they believe is in the patient's best interests. Risk communication may be omitted if it is thought to be in the patient's best interests.

With the *shared-decision making* (SDM) model, the doctor again listens to the patient's story but then involves the patient in decision-making to the extent desired by the patient. Risk communication is integral to the SDM model, particularly at the stage at which options are described and the harms and benefits associated with each option discussed.<sup>2</sup> At least some information must be both provided and discussed to enable the patient to be involved in the decision-making process.

For the purposes of this article, we discuss the ethical implications of using the *paternalistic* model versus the SDM model when dealing with Mr Davies, described in Table 1.

### **Paternalistic approach**

From looking at Mr Davies' QRISK2 score,<sup>3</sup> the general practitioner (GP) is likely to discuss information on dietary and lifestyle changes and then conclude that starting a statin for primary prevention is recommended. The GP explains that NICE guidance suggests that Mr Davies should be

started on a statin because of his QRISK2 score. This information is used to justify the GP's decision. The GP does not discuss the extent to which a statin would reduce Mr Davies' cardiovascular risk but does counsel him about the common adverse effects of statins and suggests that he returns if he experiences any of these.

We can consider the ethical implications of risk communication in the paternalistic approach using the three ethical principles of autonomy, utility and justice, as defined in Table 2. The paternalistic approach can easily emphasize biomedical utility over the patient's autonomous choice of best interests. The clinician's aim should be to consider the patient's situation in the light of their professional knowledge and come to a decision that they perceive would maximize utility. Risk communication might be omitted if this were thought to be in the patient's best interests.

There are, however, ethical pitfalls with the paternalistic approach. First, the patient's autonomy is ignored as they have not been involved in the decision-making process. As the patient's preferences or values have not been taken to account, this approach reduces their personal utility. It risks wrong judgements about what the patient would value, prefer and perceive to be beneficial and applicable in their personal situation. The paternalistic approach is not usually justifiable because the patient's goals and values are not taken into account and the patient is not involved in the decision-making process. Nevertheless, it remains a common model in clinical practice.

### **Shared decision-making approach**

The GP seeks to involve Mr Davies in the decision-making process, and Mr Davies appears comfortable with participating in the process. The SDM model is based on 'optional autonomy' as the patient determines the extent of their involvement in the decision-making process. The GP lists the options for treatment, including 'no action', explains the pros and cons of each option and explores the patient's expectations and concerns. In the SDM model, risk communication is 'enforced', although the degree to which it features varies.

Table 3 highlights ways that we could improve risk communication in practice. To help Mr Davies to make a decision, the GP gives him the absolute risk reduction (ARR) from statin use in the primary prevention of cardiovascular disease, as well as Mr Davies' personalized QRISK2 score. Most patients wish to know the numerical benefit of a preventive drug, and Mr Davies is grateful for this information. The GP checks Mr Davies' understanding of the information given. Mr Davies understands the information and decides to improve his diet, reduce his alcohol intake and stop smoking. He decides against a statin following discussion of the ARR in cardiovascular disease. He is not impressed by the reported benefits and is worried about the potential adverse effects discussed.<sup>4</sup>

From an ethical perspective, the improved autonomy of the SDM approach may be beneficial for patients willing to participate in decision-making but undesirable for those who want their doctor to make the decision. Enforced risk communication can unduly harm patients and may not therefore maximize overall benefit. The patient's decision may contradict current recommendations and practice, which can reduce biomedical utility, particularly at the level of population health. For example, uptake of statins is low following individualized risk communication based on the benefits

presented in terms of ARR or prolongation of life.<sup>4</sup> This is consistent with the known tensions found between public health, guidelines and informed decision-making.<sup>5</sup> Finally, if the doctor prioritizes the patient's right to share decisions, limited healthcare resources may be distributed on the basis of the patients' skills in sharing decisions rather than on medical and social need. Alternatively, the GP may be aware of the rights of patients who are less capable of sharing decisions and will not allow shared decisions to dictate resource use without constraint.

**Table 1** Mr Davies' situation

Mr Davies has just celebrated his 54th birthday. He is currently feeling well but wanted to have a check-up by his GP as his father died of a heart attack when he was 49. Mr Davies smokes 30 cigarettes a day. He drinks around 50 units of alcohol a week and takes very little exercise. He works at a local supermarket.

Examination reveals a body mass index of 34.7 kg/m<sup>2</sup> and blood pressure of 136/83 mmHg. Blood tests record a total cholesterol level of 5.8 mmol/litre with an high-density lipoprotein cholesterol of 1.3 mmol/litre. The glycated haemoglobin concentration is 39 mmol/litre.

Mr Davies' QRISK2 score is 23% over 10 years.

**Table 2**Definitions of ethical principles

	Definition
Autonomy	Deliberated self-rule. If a person has autonomy, they can make their own decisions on the basis of deliberation
Utility	The condition where benefit is maximized and harm minimized
Justice	The moral obligation to act on the basis of fair adjudication between competing claims. For justice to be fair, it is important to treat equals equally and to treat unequals unequally in proportion to the relevant inequalities

les

**Table 3** Methods used to communicate risk

### **Risk representations**

Absolute risk reduction (ARR) is a more balanced and understandable representation of risk reduction for patients and clinicians than relative risk reduction (RRR) and number-needed-to-treat (NNT). The following example describes the communication of risks related to a screening test where identical benefits are described in terms of ARR, RRR and NNT:

- *ARR*: If you have this test every 2 years, it will reduce your chance of dying from this cancer from around 4 in 1000 to 3 in 1000 over the next 10 years
- *RRR*: If you have this test every 2 years, it will reduce your chance of dying from this cancer by around one-quarter over the next 10 years
- *NNT*: If around 1000 people had this test every 2 years, 1 person would be saved from dying from cancer every 10 years.

### **Personalizing risk information**

Risk is expressed as a numerical estimate or category based on personal risk factors, for example QRISK2 for cardiovascular events. These can often be seen as more relevant by the patient. The use of risk personalization tools such as the Breast Cancer Risk Assessment Tool (<http://www.cancer.gov/bcrisktool/>) has been shown to enhance informed choice and participation in screening.

### **Decision aids**

These help to improve the patient's knowledge, accurate risk perception and participation in decision-making. They can also support shared decision-making between clinicians and patients. Option grids ([optiongrid.org](http://optiongrid.org)) are a set of decision aids that help patients and clinicians choose between alternative treatments options in a variety of conditions.

### **Framing**

'Framing manipulation' is the presentation of equivalent data in different ways. Attribute framing is the positive versus negative description of a specific attribute of a single item or state. For example, a patient recently diagnosed with colorectal cancer could be told that there is a 60% chance that they will survive for 5 years (positive framing) or a 40% chance that they will die within 5 years of the diagnosis (negative framing). Work has shown that interventions are seen as more beneficial by patients when presented using positive framing.

Goal framing, presented as a gain versus a loss, describes the consequences of performing or not performing an act. For example 'taking a statin would increase your chance of not having a heart attack' versus 'not taking a statin would increase your chance of having a heart attack'. Loss messages are seen to be most effective.

### **Natural frequencies**

With natural frequencies, numerical values are expressed as event rates in groups with or without the considered intervention. For example 'among 100 people who take a statin, 95 people will not get heart disease. Among 100 people who do not take a statin, 93 people will not get heart disease'. It is thought that the use of natural frequencies, compared with probabilities and percentages, improves understanding of risk.



### Key points

- Risk communication is an important part of clinical practice
- Different communication approaches place differing emphasis on risk communication and bring up different ethical issues
- The traditional *paternalistic* model emphasizes utility over autonomy, and risk communication can be omitted if it is not perceived to be in the best interests of the patient
- *Shared decision-making* places the emphasis on 'optional' autonomy, and risk communication is an integral requirement for this. Some feel that this approach can reduce utility with regard to the individual patient and the population as a whole

## Key references

1. Han PK, Joeke K, Elwyn G et al. Development and evaluation of a risk communication curriculum for medical students. *Patient Educ Couns* 2014; **94**: 43–9.
2. Elwyn G, Frosch D, Thomson R et al. Shared decision making: a model for clinical practice. *J Gen Intern Med* 2012; **27**: 1361–7.
3. Hippisley-Cox J, Coupland C, Vinogradova Y et al. Predicting cardiovascular risk in England and Wales: prospective derivation and validation of QRISK2. *BMJ* 2008; **336**: 1475–82.
4. Harmsen CG, Kristiansen IS, Larsen PV et al. Communicating risk using absolute risk reduction or prolongation of life formats: cluster-randomised trial in general practice. *Br J Gen Pract* 2014; **64**: e199–207.
5. Trevena L. Assessing, communicating, and managing risk in general practice. *Br J Gen Pract* 2014; **64**: 166–7.

## Further reading

Ahmed H, Naik G, Willoughby H et al. Communicating Risk. *BMJ* 2012; **344**: e3996.

Eriksson T, Nilstun T, Edwards A. The ethics of risk communication in lifestyle interventions: consequences of patient centredness. *Health Risk Soc* 2007; **9**: 19–36.

Gillon R. Medical ethics: four principles plus attention to scope. *BMJ* 1994; **309**: 184–8.

Hoffman TF, Legare M, Simmons K et al. Shared decision making: what do clinicians need to know and why should they bother? *Med J Aust* 2014; **201**: 35–9.

Thomson R, Murtagh M, Khaw F-M. Tensions in public health policy: patient engagement, evidence-based public health and health inequalities. *Qual Saf Health Care* 2005; **14**: 398–400.

### Test yourself

To test your knowledge based on the article you have just read, please complete the questions below .

Question 1. A 50-year-old woman with no previous medical history presented to her GP to discuss mammography screening. She had no family history of cancer, had had her first period aged 13 and had delivered her first child when she was age 23. She wished to know more about mammography screening before making a final decision. A variety of consultation approaches could have been used for this consultation, each with different ethical stands and goals.

**Which of the consultation approaches below is most in keeping with the shared decision-making approach?**

- A. The GP uses their knowledge of mammography to make a decision on whether they think mammography is in the patient's best interest. The GP gives little information about the benefits and harms of mammography screening. The ethical emphasis is on utility and justice over autonomy
- B. The GP provides information on the harms and benefits of mammography screening. They involve the patient in decision-making to the extent she desires. There is 'optional' autonomy but mandatory information provision
- C. The GP gives information on the harms and benefits of mammography screening. They then leave it up to the patient to make the final decision. The ethical emphasis is on autonomy, with the patient having to make the final decision
- D. The GP allows the patient to direct the consultation regarding mammography screening, listening to her views and concerns. The GP does not give their views on mammography screening but rather acts as a listener, facilitating the patient's story and allowing the patient to make her decision. The ethical emphasis is on autonomy and respecting the patient's right to set the agenda
- E. The GP allows the patient to direct the consultation regarding mammography screening, listening to her views and concerns. The patient asks the GP about the benefits and risks of mammography and they discuss this, allowing the patient to reflect on how compatible they are with her situation. The GP primarily acts as a listener, facilitating the patient's story and allowing the patient to make a decision herself. The ethical emphasis is on autonomy and respecting the patient's right to set the agenda

Answer: B.

Feedback: A represents a paternalistic approach, with the GP making a decision based on what they perceives to be the patient's best interests. B represents a shared decision-making approach, and the patient is involved in decision-making to the extent she desires. C represents an informed choice approach; there is mandatory information provision but the patient is made to make the final decision. D and E represent a narrative consultation approach in which the GP listens to the patient's story and facilitates further discussion.

Question 2. A 60-year-old gentleman with known ischaemic heart disease presented to his GP to discuss bowel cancer screening. His father had died from stomach cancer aged 64. The patient wished to know more about bowel screening before making a final decision on whether to take part. His GP informed him that if he had bowel screening every 2 years, it would reduce his chance of dying from bowel cancer from around 28 in 100,000 to 23 in 100,000 over the next 10 years.

**What is the absolute risk reduction of mortality from bowel cancer from bowel cancer screening?**

- A. 0.82
- B. 20,000
- C. 5 in 100,000
- D. 5 in 1000
- E. 0.6

Answer: C.

Feedback: Answer A represents the relative risk, which is calculated by the absolute risk in the treatment group (ART) divided by the absolute risk in the control group (ARC). B represents the number-needed-to-treat, which is calculated by:  $1/\text{absolute risk reduction}$ . C represents the absolute risk reduction, which is calculated by:  $\text{ARC} - \text{ART}$ . D and E are both wrong.

Question 3. A 59-year-old gentleman with a history of rheumatoid arthritis presented to his GP as his rheumatologist had advised him to see the GP regarding his cardiovascular risk status. The patient had been meaning to do this as his father had died at the age of 58 from a myocardial infarction. The patient has no cardiovascular history and has never smoked. Examination revealed a body mass index of  $24 \text{ kg/m}^2$  and blood pressure of 148/92 mmHg. Blood tests showed a total cholesterol/HDL ratio of 4.5. The patient's QRISK2 score was 21.4% over 10 years. The GP recommended that the patient should start atorvastatin 20 mg daily. Before doing this, the patient wanted to know how effective atorvastatin would be in reducing his risk of having a cardiovascular event.

**Which of the following representations of risk reduction should be used by the GP?**

- A. Relative risk reduction
- B. Number-needed-to-treat
- C. Absolute risk reduction
- D. Odds ratio
- E. Prolongation of life

Answer: C.

Feedback: Answer A makes treatment benefits and changes in risk seem larger than they actually are. B tends to be less well understood by patients and clinicians than relative risk reduction and absolute risk reduction. C is seen to be a more accurate representation of risk than relative risk reduction and is better understood than the number-needed-to-treat. D is commonly interpreted wrongly by patients and doctors. When risk is communicated using E, it usually results in a much lower proportion of people choosing therapy compared with other representations of risk reduction such as absolute risk reduction. Although it can be argued that this reduction of uptake represents informed choice, it is at odds with the public health strategy to reduce cardiovascular risk.